

**HEALTH CARE NEEDS
OF CHILDREN WITH DISABILITIES
ON MEDICAID :
RESULTS OF CAREGIVER SURVEY

FINAL REPORT**

Submitted to:
Center for Child and Family Health, Department of Human Services
Disability and Health Program, Department of Health

A Needs Assessment Conducted by:
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TABLE OF CONTENTS

	<u>Page</u>
I. Executive Summary	vii
II. Background	1
III. Methods	4
Sample Selection	4
Survey Design	5
Data Collection and Management	6
IV. Results	7
Sample Respondents	7
Characteristics of Sample	9
Physical, Mental and Developmental Disability Categories	13
Health Status and Functional Limitation	18
Primary Care Utilization	21
Specialty Care Utilization	25
Emergency Department Utilization	29
Hospital Utilization	32
Satisfaction with Care	36
Barriers to Care	38
Unmet Health Needs	40
References	43

LIST OF TABLES

	<u>Page</u>
Table 1: Reasons for Loss to Follow-up of Selected Random Sample	8
Table 2: Characteristics of Sample Respondents and Total Population	10
Table 3: Geographic Distribution of Sample Respondents and Total Population	11
Table 4: Types of Primary Disabilities Reported by Caregivers	14
Table 5: Measures of Health Status and Functional Limitation	19
Table 6: Utilization of Preventive Primary Care in Past Year	22
Table 7: Utilization of Acute Primary Care in Past Year	24
Table 8: Utilization of Specialty Care in Past Year	26
Table 9: Emergency Department Utilization in Past Year	30
Table 10: Hospital Utilization on Past Year	33
Table 11: Satisfaction with Care	37
Table 12: Barriers to Care Faced by Caregivers by Disability Category	39
Table 13: Availability of Services for Rhode Island Children with Disabilities	41
Table 14: Top Ten Unmet Needs of Children with Disabilities on Medicaid	42

LIST OF FIGURES

	<u>Page</u>
Figure 1: Distribution of Respondent Children with Disabilities by Age and Sex	12
Figure 2: Distribution of Respondent Disability Categories by Age	16
Figure 3: Distribution of Respondent Disability Categories by Gender	17
Figure 4: Average Days of School Missed Due to Primary Disability in Past Year by Age and Disability Category	20
Figure 5: Distribution of Preventive Visits by Age Group	23
Figure 6: Average Specialty Visits in Past Year by Disability Category	28
Figure 7: Ever Been Treated in Emergency Room in Past Year by Disability Category	31
Figure 8: Ever Been Admitted to Hospital in Past Year by Disability Group	34
Figure 9: Average Number of Nights Spent in Hospital in Past Year by Disability Category	35

LIST OF APPENDICES

	<u>Page</u>
Appendix 1: Survey Subgroup	44
Appendix 2: Survey Instrument	47
Appendix 3: Letters Sent to Caregivers	60
Appendix 4: Sample Weights	62
Appendix 5: Distribution of Primary ICD9 Diagnoses by Disability Category for Survey Respondents	64

EXECUTIVE SUMMARY

In order to understand the health care needs of Rhode Island children and adolescents with disabilities on Medicaid the Department of Human Services and the Department of Health funded a caregiver survey. A representative statewide sample of 257 caregivers of children with disabilities aged 1-21 was interviewed from October 1997 through December 1997. Summary findings are listed below.

- X Caregivers of children with physical, mental and developmental disabilities were interviewed by telephone or in person. Children with physical disabilities comprised up 35.2% of the sample; children with mental disabilities comprised 27.3% of the sample; and children with developmental disabilities comprised 37.5% of the sample.

- X Measures of health status and functional limitation show that 53.5% of the children have two or more disabilities; 49.5% needed help with their personal care; 73.7% were limited in the kind or amount of activity they can do; and 7.1% were unable to take part at all in age-appropriate activities.

- X Utilization measures show that 85.6% of the children had a preventive health visit in the past year. On average, children with disabilities received -- 2.5 preventive primary care visits; 3.4 acute primary care visits; and 18.2 specialty care visits for a total of 24.1 health care visits per year.
- X Specialty care visits varied by disability type. Children with mental disabilities had twice the rate of specialty care visits as children with either physical or developmental disabilities. On average, children with developmental disabilities had 12.6 specialty care visits per year; children with physical disabilities had 15.8 specialty care visits per year; and children with mental disabilities had 29.3
- X Emergency department utilization was 2,693 visits per 1000 children with disabilities. Children with physical disabilities had the highest emergency department visits rate at 4,729 per 1000.
- X The hospitalization rate was 417 admissions per 1000 children. Children with physical disabilities had the highest hospital admission rate at 700 admission per 1000 children. However, children with mental disabilities had the highest number of days spent in the hospital. Of children who were hospitalized, children with mental disabilities, on average, spent 72.6 days in the hospital per year, compared to 24 days for children with physical disabilities and only

3.2 days for children with developmental disabilities.

- X Overall satisfaction with care was high; 95% of caregivers were satisfied or very satisfied with their child=s last visit to the doctor.
- X Caregivers of children with mental disabilities faced the most barriers to care. They were more likely to feel overwhelmed due to their child=s needs, unable to work due to caretaking responsibility, unable to find child care and not able to get support from family and friends.
- X The most significant unmet needs related to support and ancillary services to caregivers. These needs included parent=s support groups, respite care, information on primary condition, parent education, transportation and day care. Unmet direct care needs for the child included case management, dental care and mental health counseling.

BACKGROUND

Prevalence of Disability

In the United States, it is estimated that 3%-31% of all children are affected by chronic conditions (1-7) and that 7%-13% of all children experience a disability or activity limitation as a result of a chronic physical or mental condition (3)(5)(7). These range of prevalence estimates are wide because different methods and definitions are used in collecting prevalence data (3)(6)(7). Prevalence rates vary depending on the sample being studied (e.g. population-based or clinic-based), how the data is collected (e.g. caregiver survey vs. medical record), or what types of disabilities are included (e.g. physical only or physical and mental).

Risk Factors for Disability

Two cross sectional national surveys that measure disability show that disability is higher among boys, African-Americans and families living in poverty (1)(7). Childhood disability has substantial health and social impacts including adverse effects on child development, increased caretaking responsibilities for families, demands on the educational system for greater resources, and higher health care utilization and hospitalization rates (5)(7).

Classifying Disability

In recent years, there has been a move away from identifying disabilities by relying on lists of medical diagnoses; instead recent recommendations classify disabling conditions by the functional limitation that emerges as a result of diagnosis (8)(9). Using this method, disability is defined by severity of impairment, rather than diagnosis. In addition, several policy studies have recommended classifying disabilities in three subgroups because they each require different configurations of health care services (4)(5)(6). These three subgroups include:

- ! Children with physical disabilities, including, but not limited to, diabetes, asthma, sickle cell anemia, and spina bifida. These children have complex physical conditions which are rare, severe, or disabling and require pediatric sub-specialty services on an ongoing basis.
- ! Children with developmental disabilities, including mental retardation, learning disabilities and sensory impairments. These children manifest some degree of delay or disability in communication, cognition, mobility, self-direction, and self-care.
- ! Children with mental disabilities, including children with serious emotional and behavioral disorders such as attention deficit disorder, conduct disorders, schizophrenia, and manic depression.

Purpose of Rhode Island Survey

In order to understand the needs of Rhode Island children and adolescents with disabilities, the Department of Human Services and the Department of Health contracted with MCH Evaluation, Inc. to conduct a survey that would determine access to and quality of primary and specialty health care that children with disabilities on Medicaid are receiving. The purpose of the survey was to describe the characteristics of Rhode Island children with disabilities; to determine utilization rates of primary care, specialty care, and emergency and hospital care; to measure satisfaction with care and barriers to care; and to calculate unmet health and social need for these children and their families.

METHODS

Sample Selection

The population studied was the 4,314 Rhode Island children and adolescents with disabilities on fee-for-service Medical Assistance, aged 1-21, who had been on SSI (88.6%) or other State waiver programs (11.3%), from July 1, 1996 to June 30, 1997. These selection criteria were made so a child or adolescent would be on the Medicaid program for at least one year.

The population sample was stratified by four resource consumption categories (i.e. annual Medicaid claims paid) and four disability age categories. The four resource consumption categories were: 1) no annual claims paid; 2) \$1-\$4,999; 3) \$5,000-\$19,000; and 4) \$20,000-\$400,000. The four disability age categories were: 1) 1-4 ; 2) 5-11; 3) 12-17; 4) 18-21. These age categories are classified according to the major activities appropriate for their age (i.e. age 1-4 is play; age 5-11 is school; age 12-17 is school; and age 18-21 is school or work).

A stratified random sample of 400 was selected. Twenty five children were randomly selected from each of the 16 resource/disability age cells. High resource users and children 1-4 were over-sampled so there would be sufficient numbers for analysis. It was expected that 15% of the sample would not be eligible to be

interviewed because the eligibility data file was not updated. In addition, it was expected that 15% of the sample would not be located.

Survey Design

The survey was designed in collaboration with experts from the State Department of Health, Department of Human Services, Department of Education, Department of Children Youth and Families, Developmental Disabilities Council, Brown University, parent advocacy groups and parents of children with disabilities (Appendix 1). This group met six times from July 2, 1997 to September 30, 1997 to design the Health Care Needs of Children with Disabilities Survey (Appendix 2).

Questions were designed to measure type of disability, functional limitation, primary care utilization, specialty care utilization, emergency department utilization, hospitalization, satisfaction with care, barriers to care and unmet health services needs. There was a ten-page limit to the questionnaire, both because of cost and the group felt it would be a burden on families and would affect response rates if it took more than 15 minutes to answer the survey. The survey subgroup reviewed and commented on nine drafts of the survey. The survey was piloted by six parents of children with disabilities. The survey was reviewed and approved by the Rhode Island Department of Health's Human Subjects Review Committee.

Data Collection and Management

Four experienced interviewers were hired and trained. All interviewers attended a two-hour training session that entailed interviewing skills, survey coding and practical role plays. A letter, from the Directors of Health, Director of Human Services, and Family Voices of Rhode Island was mailed out to the parents and caregivers of the randomly selected sample of 400 notifying them that an interviewer would be calling them (Appendix 3). Interviews were conducted from October 1, 1997 to December 10, 1997. Resource packets were sent to all parents and caregivers who were selected to participate.

The project director, data manager and the four interviewers met weekly to review surveys and make data management decisions. Each interviewer maintained a follow-up log on surveys assigned to her. The data manager maintained a follow-up log to keep track of each survey and a data management decision notebook to document coding decisions. The project director reviewed all primary and secondary disabilities listed by the caregiver and assigned them to an International Classification of Disease Code (ICD9) (10).

RESULTS

Sample Respondents

Table 1 shows the reasons for loss-to-follow up of the selected random sample of 400. Two hundred fifty-seven (257) caregivers completed the survey. This represents a 64.3% response rate. The majority of the caregiver respondents were parents (90.2%). The major reason for not locating a caregiver was an unknown or unlisted current telephone number. There was no differences between the respondents and non-respondents on age, sex, Medicaid claims paid, Medicaid category and city of residence.

Since high resource users and children less than five were over sampled, the sample of 257 was weighted to reflect the total population of 4,314 children and adolescents with disabilities in Rhode Island. Appendix 4 shows how these weights were calculated for each age and resource cell. All results displayed in the report are weighted.

TABLE 1: REASONS FOR LOSS TO FOLLOW-UP
OF SELECTED RANDOM SAMPLE
(n =400)

	<u>N</u>	<u>%</u>
<u>Located</u>		
Respondents - completed interview	257	64.3
Non-respondents		
Inactive Case*	25	6.3
Deceased*	9	2.2
Moved out of state*	6	1.5
Declined	5	1.2
Duplicate*	4	1.0
Language	3	0.7
Other	7	<u>1.8</u>
		79.0
<u>Not Located</u>		
Unable to contact - no information	67	16.8
Unable to contact - some information	17	<u>4.2</u>
		21.0

*not eligible to be interviewed n=44 - (400-44=356)
 response rate removing those children not eligible = $\frac{257}{356} = 72.2\%$

Characteristics of Sample

Table 2 and Table 3 show characteristics of the sample respondents (n=257) compared to selected characteristics of the total population (n=4,314). Since the sample was stratified by age and resource use, then weighted using these categories, the distribution of the sample on these characteristics is almost identical to the population. The sample distribution represented the total population by Medicaid aid category and city of residence.

For this sample, the majority of annual Medicaid paid claims were in the \$1,000-4,999 range and 32.8% of the sample had private insurance in addition to Medicaid. Males represented 57% of the sample. The distribution of males varied across disability age groups. Figure 1 shows the variability in gender distribution by age groups. In the youngest age group (ages 1-4), males made up 73.4% of the sample. In the 18-21 age group, males made up 49.8% of the sample. Some explanations for this variability include a higher incidence of males with disabilities at birth with a higher mortality rate (Note: In this sample of 400, of the 9 deaths that occurred, 7 were to males.). In addition, diagnoses change over a time and females may be more likely to seek medical care for disabilities.

TABLE 2: CHARACTERISTICS OF SAMPLE RESPONDENTS
AND TOTAL POPULATION*

	<u>Sample</u> (n=257)	<u>Population*</u> (n=4,314)
<u>Age</u>		
1-4	9.8%	9.8%
5-11	36.8	36.4
12-17	31.9	34.5
18-21	21.5	19.5
<u>Annual Medicaid Claims Paid**</u>		
None	34.9	34.4
\$1-4,900	56.5	57.0
\$5,000-19,999	4.8	4.9
≥\$20,000	3.8	3.8
<u>Medicaid Aid Category</u>		
Blind/SSI (AB)	0.7	0.7
SSI (AD)	88.1	85.7
SSI/1619B (BD)	1.1	2.2
Institutionalized (LD)	6.5	8.5
Waiver (WD)	3.7	2.8
<u>Sex</u>		
Male	57.0	NA
Female	43.0	
<u>Language</u>		
English	90.4	NA
Spanish	9.6	
<u>Insurance Status</u>		
Medicaid only	67.2	NA
Medicaid and Private (Dual Coverage)	32.8	

* Total Population = 4,314 RI children and adolescents ages 1-21
with disabilities on Medicaid from July 1, 1996 - June 30, 1997

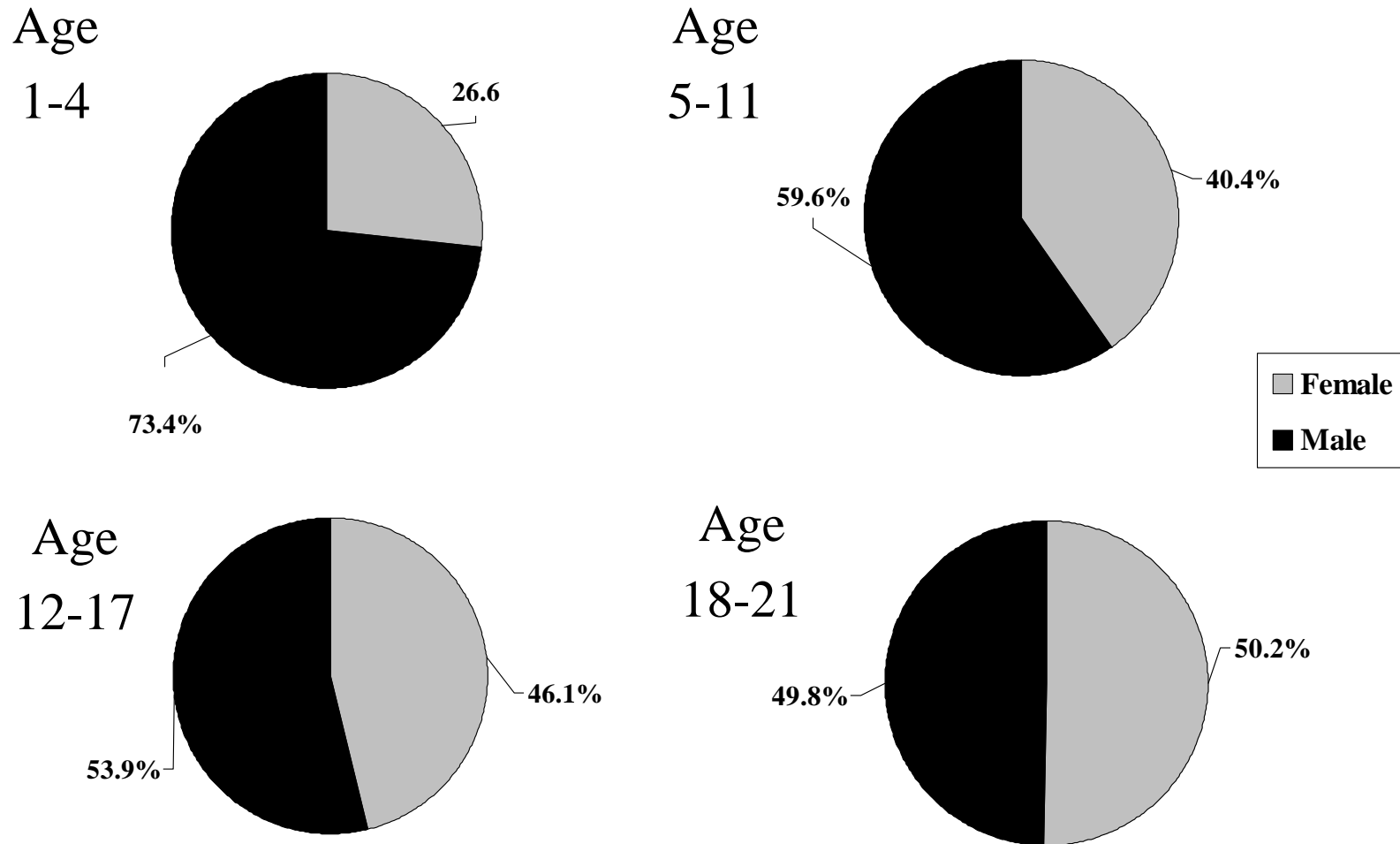
** = Represents claims with dates of service between July 1, 1996 - June 30, 1997 and paid as of
August 15, 1997; there is an anticipated additional claims backlog so these amounts do not
represent all services provided over this one-year period.

Data Source: Medicaid Management Information System (MMIS)
NA = not available

TABLE 3 : GEOGRAPHIC DISTRIBUTION OF SAMPLE RESPONDENTS
AND TOTAL POPULATION

<u>City/County Distribution</u>	<u>Sample</u> (n=257)	<u>Population</u> (n=4,314)
Bristol County	2.0%	2.5%
Barrington	0.0	0.7
Bristol	1.8	1.2
Warren	0.2	0.6
Kent County	13.2	10.8
Coventry	2.5	2.0
East Greenwich	0.7	0.5
Warwick	7.0	5.4
West Greenwich	0.7	0.3
West Warwick	2.3	2.6
Newport County	6.6	4.7
Jamestown	0.0	0.2
Little Compton	0.0	0.1
Middletown	1.2	1.1
Newport	4.7	2.2
Portsmouth	0.2	0.6
Tiverton	0.5	0.5
Providence County	74.4	76.1
Burrillville	0.5	1.0
Central Falls	4.0	3.9
Cranston	5.9	5.1
Cumberland	2.5	1.2
East Providence	4.7	3.4
Foster	0.0	0.2
Glocester	0.2	0.5
Johnston	1.1	1.5
Lincoln	0.0	1.0
North Providence	2.6	1.6
North Smithfield	0.1	0.4
Pawtucket	10.1	9.8
Providence	35.0	38.4
Scituate	0.0	0.2
Smithfield	0.4	0.7
Woonsocket	7.3	7.2
Washington County	4.6	5.9
Charlestown	0.7	0.4
Exeter	0.0	0.2
Hopkinton	0.1	0.3
Narragansett	0.2	0.4
New Shoreham	0.0	0.0
North Kingstown	0.1	1.3
Richmond	0.1	1.1
South Kingstown	2.0	0.9
Westerly	1.4	1.3
	100%	100%

Figure 1: Distribution of Respondent Children with Disabilities by Age and Sex (n=257)



Data Source: Caregiver Survey (n= 257)

Physical, Mental and Developmental Disability Categories

Each caregiver identified the child's "primary disabling condition in the past year." Each condition was assigned an ICD9 diagnosis code and then was classified as a physical, mental or developmental disability. Table 4 shows the results of this classification. (Note: Appendix 5 shows the distribution of each ICD9 diagnosis by the three disability classifications.)

The physical disability category comprised 35.2% of the sample, many of which were low prevalence complex physical disabilities. The individual diagnosis with the highest prevalence in the physical category was cerebral palsy (8.7%).

Mental disabilities comprised 27.3% of the total sample. Attention-deficit disorder or Attention-deficit hyperactivity disorder was the mental disability with the highest prevalence (17%).

Almost thirty-eight percent (37.5%) of the primary disabling conditions from this sample were classified in the developmental disability category. Learning disability and pervasive developmental delay comprised the largest single diagnosis in this category (18.1%).

TABLE 4: TYPES OF PRIMARY DISABILITIES* REPORTED BY CAREGIVERS		
CATEGORY	TYPES OF DISABILITIES REPORTED**	PERCENT (n=257)
PHYSICAL	Brain tumor, Neuroblastoma, Lymphoma, Leukemia, Sotos Syndrome, Metabolic Disorder, Wilson=s Disease, Cystic Fibrosis, Sickle Cell Anemia, Hemophilia, Hydrocephalus, Hemiparesis, Cerebral Palsy, Paralysis, Epilepsy, Muscular Dystrophy, Blindness, Deafness, Asthma, Tracheomalasia, Short Gut, Kidney Defect, Lupus, Muscular Disorder, Spina Bifida, Microcephalus, Heart Defect, Imperforated Anus, Scoliosis, Gastroschisis, Epidermolysis Bullosa, Prader Willi Syndrome, Prematurity, Seizure Disorder, Traumatic Brain Injury, Fracture, Near Drowning	35.2%
MENTAL	Serious Emotional or Behavioral Disorder, Schizophrenia, Manic Depression, Psychoses, Anxiety, Post Traumatic Stress, Attention Deficit Disorder, Attention Deficit Hyperactivity Disorder	27.3%
DEVELOPMENTAL	Learning Disability, Pervasive Developmental Delay, Mental Retardation, Autism, Down Syndrome, Speech Disorder	37.5%

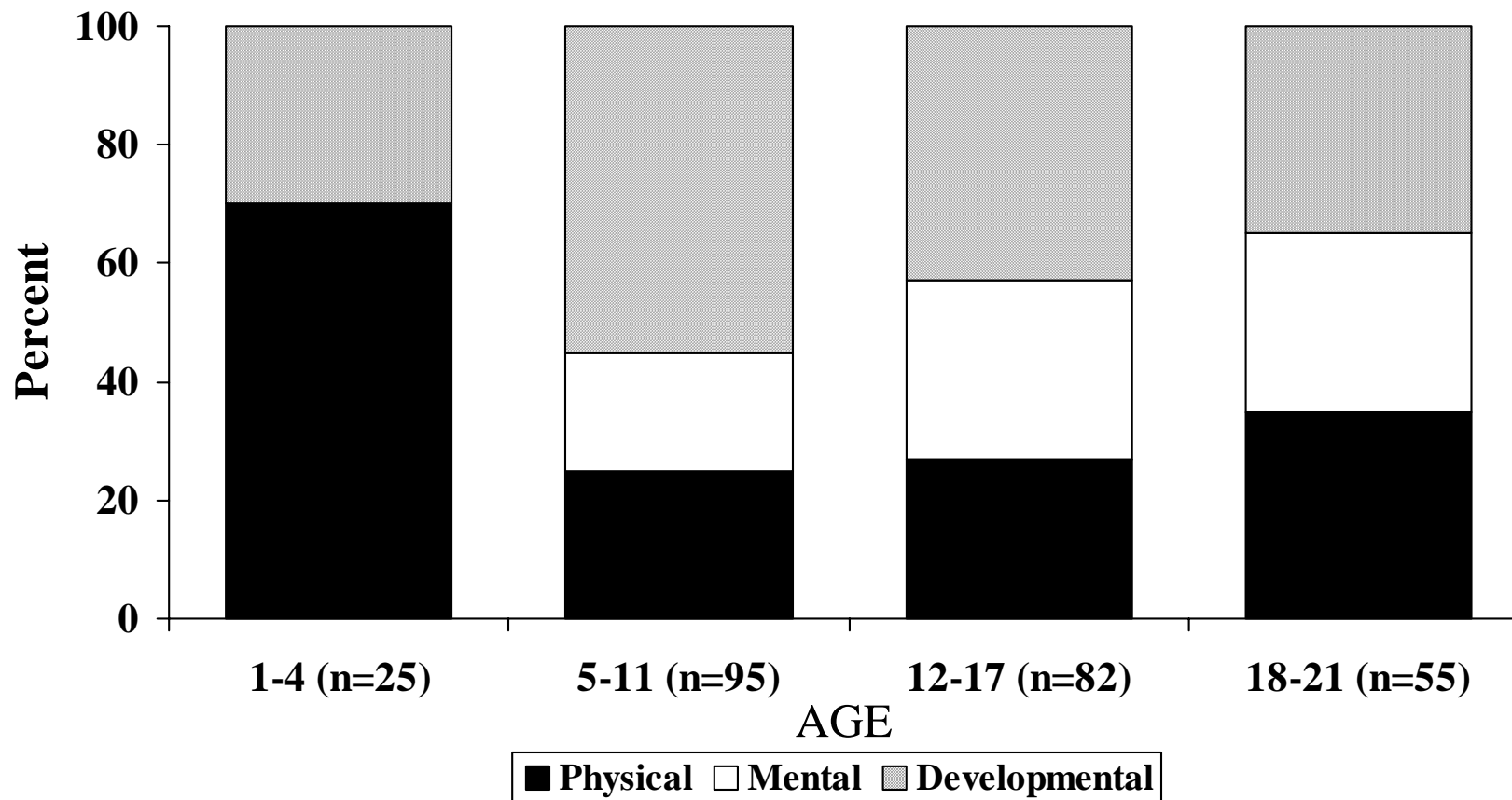
Data Source: Caregiver Survey

- * A child=s primary disabling condition in past year@
 (if more than one, caregiver selected one which required most time spent with doctor or provider)
- * * See Appendix 6 for frequency distribution of all disabilities by ICD9 codes

Figure 2 displays the distribution of three disability categories partitioned by the four age groups. In the 1-4 age group, the overwhelming majority of the primary disabilities were physical (70%). There were no children diagnosed with mental disabilities in this youngest age group. Developmental disabilities had the highest distribution in the 5-11 age group. This is primarily due to entrance into school and the diagnosis of learning disabilities. Physical disabilities rose again in the 18-21 age group due to a higher distribution of injury-related disability and sensory loss (i.e., blindness and deafness).

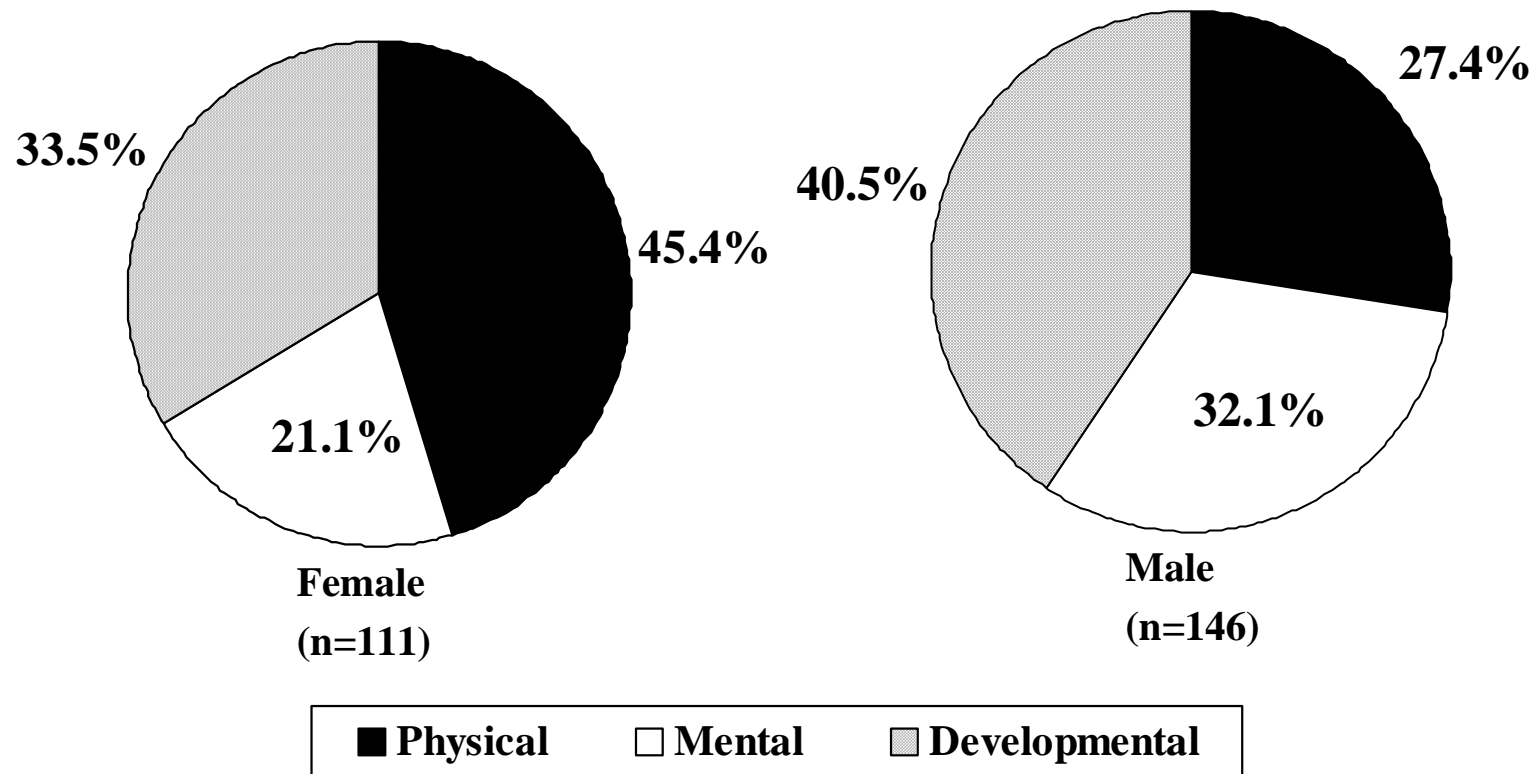
Figure 3 shows that the distribution of disability differs by gender. Females were more likely than males to have a physical disability. Forty-five percent (45.4%) of the disabilities females were classified as physical compared to 27.4% for males. The rate of cerebral palsy was higher among females, especially with older age groups. The survivorship of females with physical disabilities may also be higher than for males. Males had a higher percentage of mental and developmental disabilities. Males had rates of attention deficit disorder/attention deficit hyperactivity disorder that were five times higher than females in the 5-11 age category.

Figure 2: Distribution of Respondent Disability Categories by Age



Data Source: Caregiver Survey (n=257)

Figure 3: Distribution of Respondent Disability Category by Gender



Data Source: Caregiver Survey (n=257)

Health Status and Functional Limitation

The survey had several questions on the functional status of the children and adolescents. Table 5 shows that the majority of children had more than one disability (53.5%) and almost one half needed help with their personal care (49.5%). Almost three-quarters of the children (73.7%) were limited in the kind or amount of activity they were able to do. Seven percent of the children (7.1%) were severely disabled and unable to take part at all in age-appropriate activities. It is important to measure functional limitation because children with severe impairments may have greater needs for specialty care.

Figure 4 shows the average number of days of school missed due to the primary disability. On average, the younger school-age group (i.e., ages 5-11) missed 12.4 days of school per year because of their disability. Young school-age children with physical disabilities missed the highest number of days. On average, they missed 20 days of school. In the older school-age group (i.e., ages 12-17), adolescents with mental disabilities missed the most school. Adolescents with mental disabilities missed, on average, 22 days of school each year.

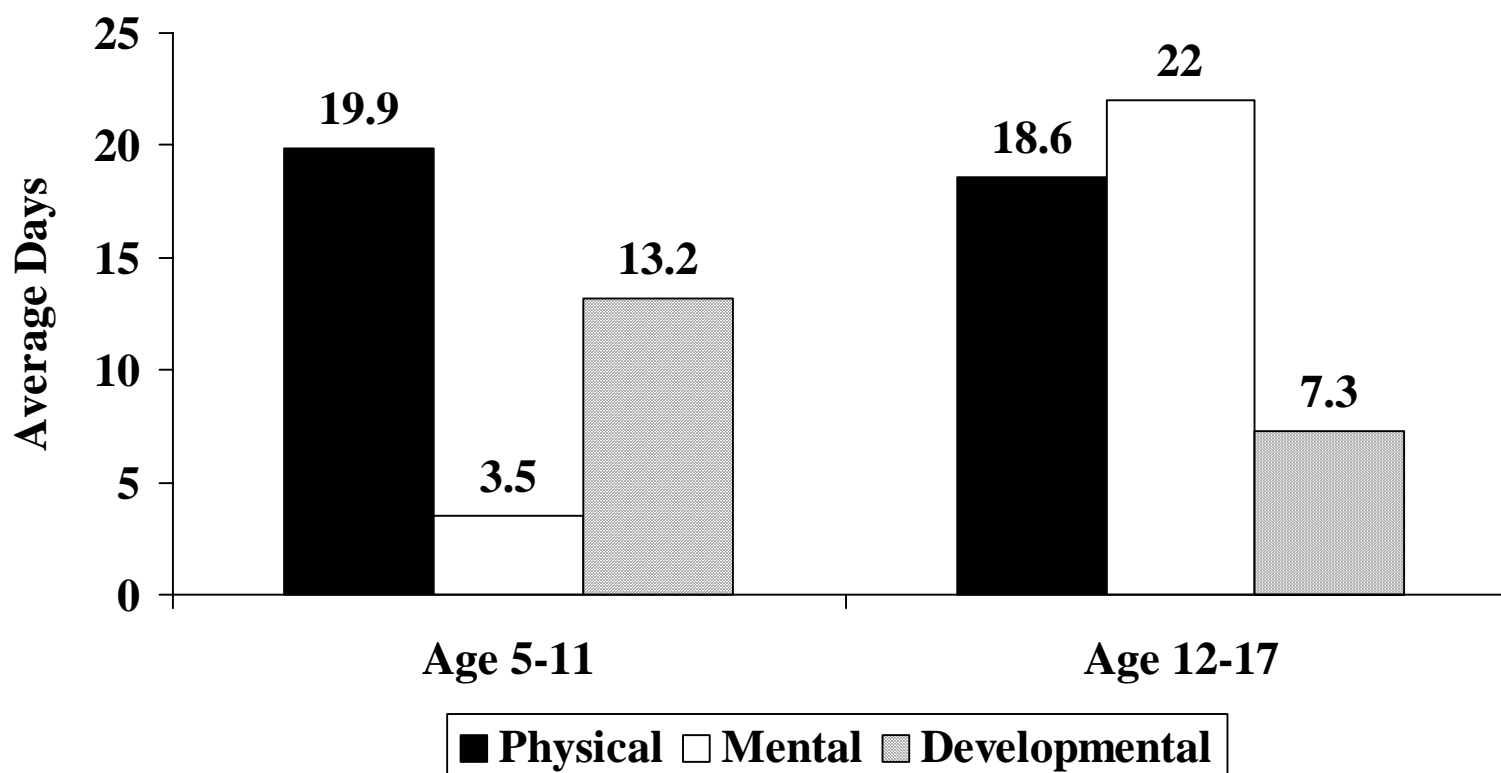
TABLE 5: MEASURES OF HEALTH STATUS
AND FUNCTIONAL LIMITATION

	<u>Percent of Children and Adolescents (n=257)</u>
<u>Number of Disabilities</u>	
One	46.5%
Two	28.0
Three or More	25.5
<u>Is Primary Disability Result of an Injury?</u>	
No	93.3%
Yes	6.7
<u>Needs Help of Other Person with Personal Care?</u>	
No	50.5%
Yes	49.5
<u>Is Able at all to Take Part in Usual Kinds of Activity*?</u>	
No	7.1%
Yes	92.9
<u>Is Limited in the Kind or Amount of Activity?</u>	
No	26.3%
Yes	73.7
<u>Days Missed of Usual Activity in Past Year?</u>	
None	36.5%
1-9 days	28.7
10-29 days	12.5
30-58 days	6.9
≥ 60 days	6.5
365 days	9.0
<u>Has the term Atechnology dependent@ been used to describe your child?</u>	
No	91.0%
Yes	9.0

Data Source: Caregiver Survey

* Usual activity by age - 1-4 play; 5-17 school; 18-21 school or work

Figure 4: Average Days of School Missed Due to Primary Disability in Past Year by Age and Disability Category



Data Source: Caregiver Survey (n=257)

Primary Care Utilization

Table 6 shows that 85.6% of the children and adolescents had a preventive health care visit in the past year. Preventive visits included "scheduled well visits from healthy check-ups." Approximately one-half (49%) went to a private physician's office; 26% went to community health centers; and 14% went to hospital clinics for preventive care. The number of preventive visits was associated with the age of the child since recommended visits decrease as the child ages. On average, children with disabilities had 2.5 preventive care visits. Children aged 1-4 had an average of 3.6 preventive visits and adolescents aged 12-17 had an average of 1.8 preventive visits. Figure 5 shows the variability in distribution of visits as age increases.

Seventy-five percent (74.6%) of the children had an acute primary care visit as defined as an "unscheduled sick visit from an acute problem." Table 7 shows that most of the children received their acute primary care at private physicians' offices (38.4%). Although none of the children received preventive visits at hospital emergency departments, 21.1% received acute primary care at the emergency department. On average, children with disabilities had 3.4 acute primary care visits.

TABLE 6: UTILIZATION OF PREVENTIVE PRIMARY CARE* IN PAST YEAR
(n=257)

Percent Who Had Preventive Visit in Past Year

No	14.4%
Yes	85.6

Percent Usual Site of Care for Preventive Visits (n=257)

Private physician office	49.0%
Community health center	25.9
Hospital clinic - primary care	14.2
Staff HMO	6.5
Hospital clinic - specialty care	3.3
School	1.1
Emergency Department	0.0
Other	0.0

Average Number of Preventive Visits (0-52)** 2.5

Average Number Preventive Visits by Age

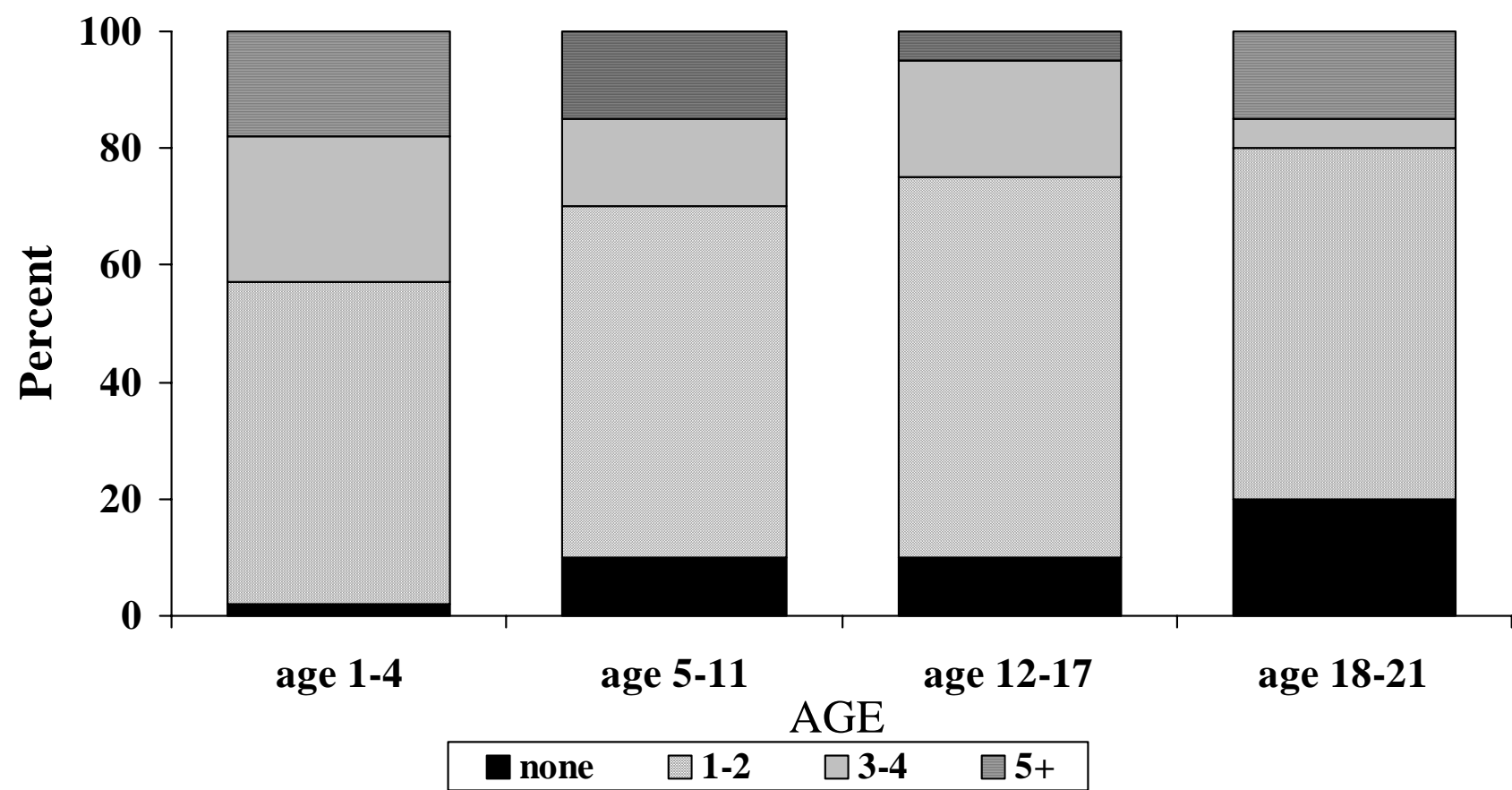
< 5 years old	3.6
6-11 years old	3.1
12-17 years old	1.8
18-21 years old	2.2

Data Source: Caregiver Survey

* Preventive primary care = Ascheduled well visits for healthy check-ups@

** () = Range of visits

Figure 5: Distribution of Preventive Visits by Age Group



Data Source: Caregiver Survey (n=257)

TABLE 7: UTILIZATION OF ACUTE PRIMARY CARE* IN PAST YEAR
(n=257)

Percent Who Had Acute Visit in Past Year

No	25.9%
Yes	74.6

Percent of Usual Site of Care for Acute Visits (n=212)

Private physician office	38.4%
Community health center	21.4
Hospital clinic - primary care	4.3
Staff HMO	8.6
Hospital Clinic - specialty care	4.3
School	0.0
Emergency Department	21.1
Other	0.0

Average Number Acute Visits (0-110)** 3.4

Data Source: Caregiver Survey

*Acute primary care = unscheduled sick visits for acute problems@

** () = Range of visits

Specialty Care Utilization

In the past year, 78.9% of the children and adolescents had a specialty care visit. Children with developmental disabilities were the least likely to have a specialty care visit. Thirty-four percent (33.9%) of children with a developmental disability did not have a specialty care visit compared to 13% of children with a physical disability.

As Table 8 shows, the site of care for specialty care also differed from the site of preventive care. The majority of children with disabilities went to a private provider's office (38.6%) for specialty care. Approximately one in three children with disabilities received specialty care at a hospital-based specialty care clinic. School is also a site where 14% of the sample received their specialty care. This group consisted mainly of children with developmental disabilities who received their speech and physical therapy at school.

On average, all children and adolescents in the sample had 18.2 specialty care visits per year. Since the average number of specialty visits was affected by outlier values (i.e., 2% of the sample had over 200 specialty care visits), the median specialty care visits is also reported in Table 8. The median specialty care visits was six (i.e., 50% of the children had less than six specialty care visits and 50% of the children had over six specialty care visits).

TABLE 8: UTILIZATION OF SPECIALTY CARE IN PAST YEAR
(n=257)

Percent Who Had Specialty Care Visit in Past Year

No	21.1%
Yes	78.9

Percent Usual Site of Care for Specialty Visit (n=215)

Private provider office	38.6%
Community Health or Mental Health Center	6.9
Hospital Clinic - primary care	9.6
Staff HMO	0.8
Hospital Clinic - specialty care	30.3
School	13.6
Emergency Department	0.0
Other	0.2

Average Number of Specialty Care Visits(0-312)** 18.2

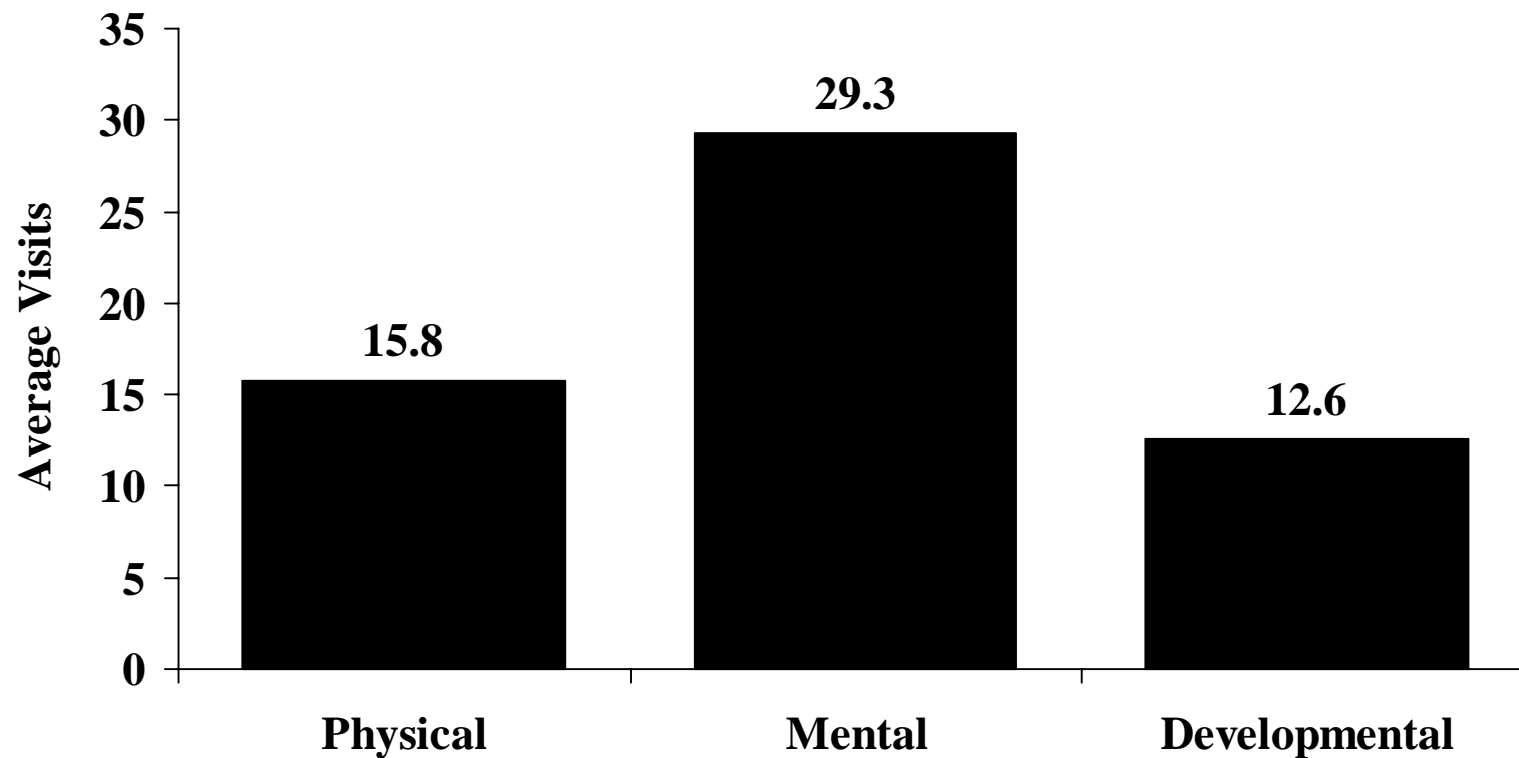
Median Number of Specialty Care Visits 6

Data Source: Caregiver Survey

** () = Range of visits

Figure 6 shows that the average number of specialty care visits varied by primary disability group. Children and adolescents with mental disabilities had the highest average number of specialty visits. The average number of specialty visits for children with mental disabilities was 29.3; for children with physical disabilities 15.8; and children with developmental disabilities 12.6.

Figure 6: Average Specialty Visits In Past Year
By Disability Category



Data Source: Caregiver Survey (n=257)

Emergency Department Utilization

Table 9 shows that fifty percent of the sample (49.9%) used the emergency department. The average number of emergency room treatments per 1,000 children with disabilities was 2,694. This rate varied by disability group, as Figure 7 shows. Children with physical disabilities had the highest rate of emergency department use (4,729 per 1,000) compared to children with mental disabilities (2,016 per 1,000) and developmental disabilities (1,248 per 1,000).

TABLE 9: EMERGENCY DEPARTMENT UTILIZATION IN PAST YEAR
(n=257)

<u>Percent Ever Been Treated in Emergency Room</u>	
No	49.9%
Yes	50.1

<u>Average ER treatments per 1,000 children (0-110)**</u>	2,693.5
---	---------

Average ER treatments per 1,000 children with physical disabilities	4,728.8
--	---------

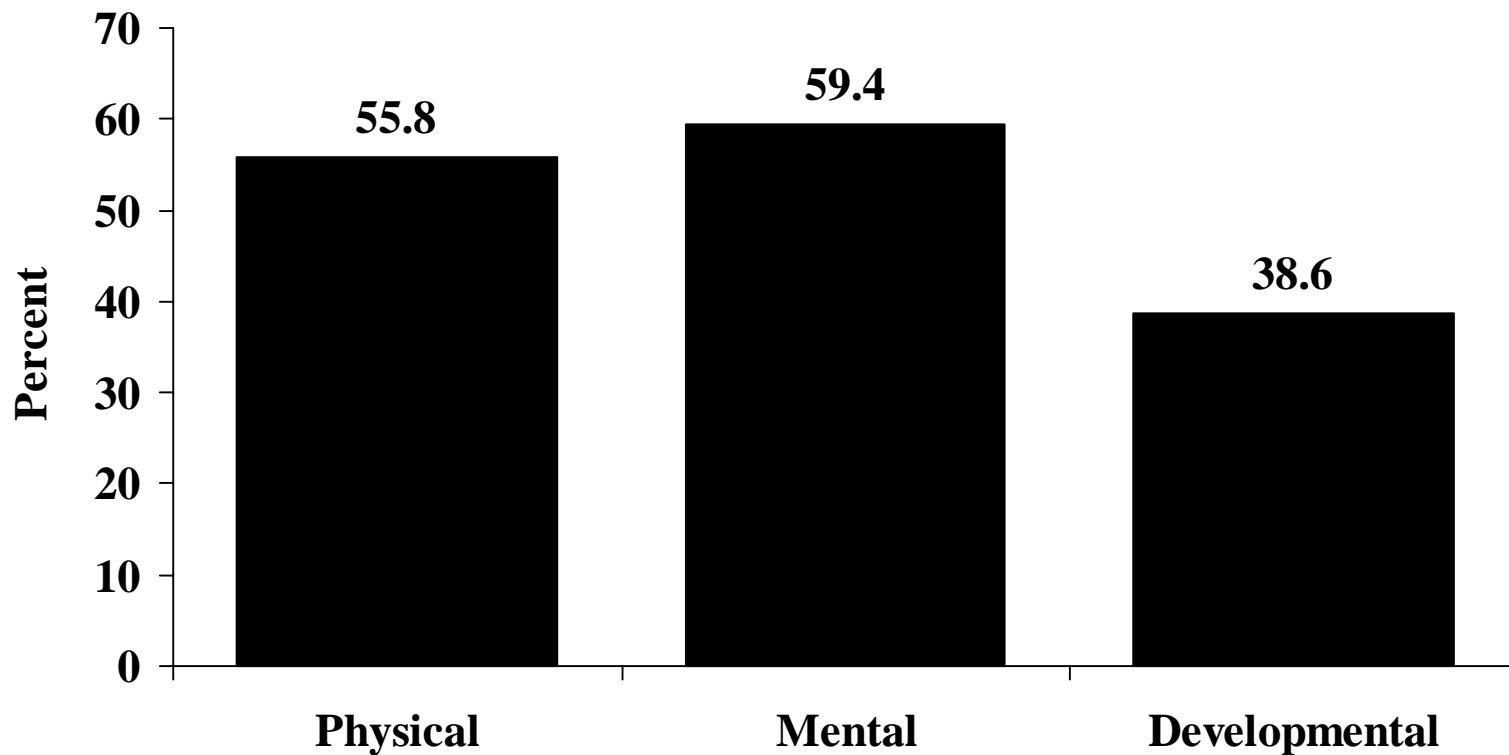
Average ER treatments per 1,000 children with mental disabilities	2,015.6
--	---------

Average ER treatments per 1,000 children with developmental disabilities	1,248.3
---	---------

Data Source: Caregiver Survey

** () = Range of visits

Figure 7: Ever Been Treated in Emergency Room in Past Year By Disability Category



Data Source: Caregiver Survey (n=257)

Hospital Utilization

Table 10 shows hospital utilization in the past year and rate of hospitalization by primary disability group. Seventeen percent (17.0%) of the sample had been admitted to the hospital in the past year. Children with physical disabilities were twice as likely as children with mental or developmental disabilities to be admitted to the hospital and their rate of hospital admissions was also the highest. The hospital admission rate for children with physical disabilities was 700 per 1000; for children with mental disabilities 405 per 1000; and children with developmental disabilities 158 per 1000.

Children with mental disabilities who were hospitalized, however, had the highest number of annual days spent in the hospital. Figure 9 shows that for children with mental disabilities, who were hospitalized, the average annual number of days spent in the hospital was 72.6 compared to 24 days for children with physical disabilities and 3.2 days for children with developmental disabilities.

TABLE 10: HOSPITAL UTILIZATION IN PAST YEAR
(n=257)

Percent Ever Admitted to Hospital Overnight

No	83.0%
Yes	17.0

Percent of Hospital Admissions out-of-state

None	81.9%
1-2	3.2
≥3	15.0

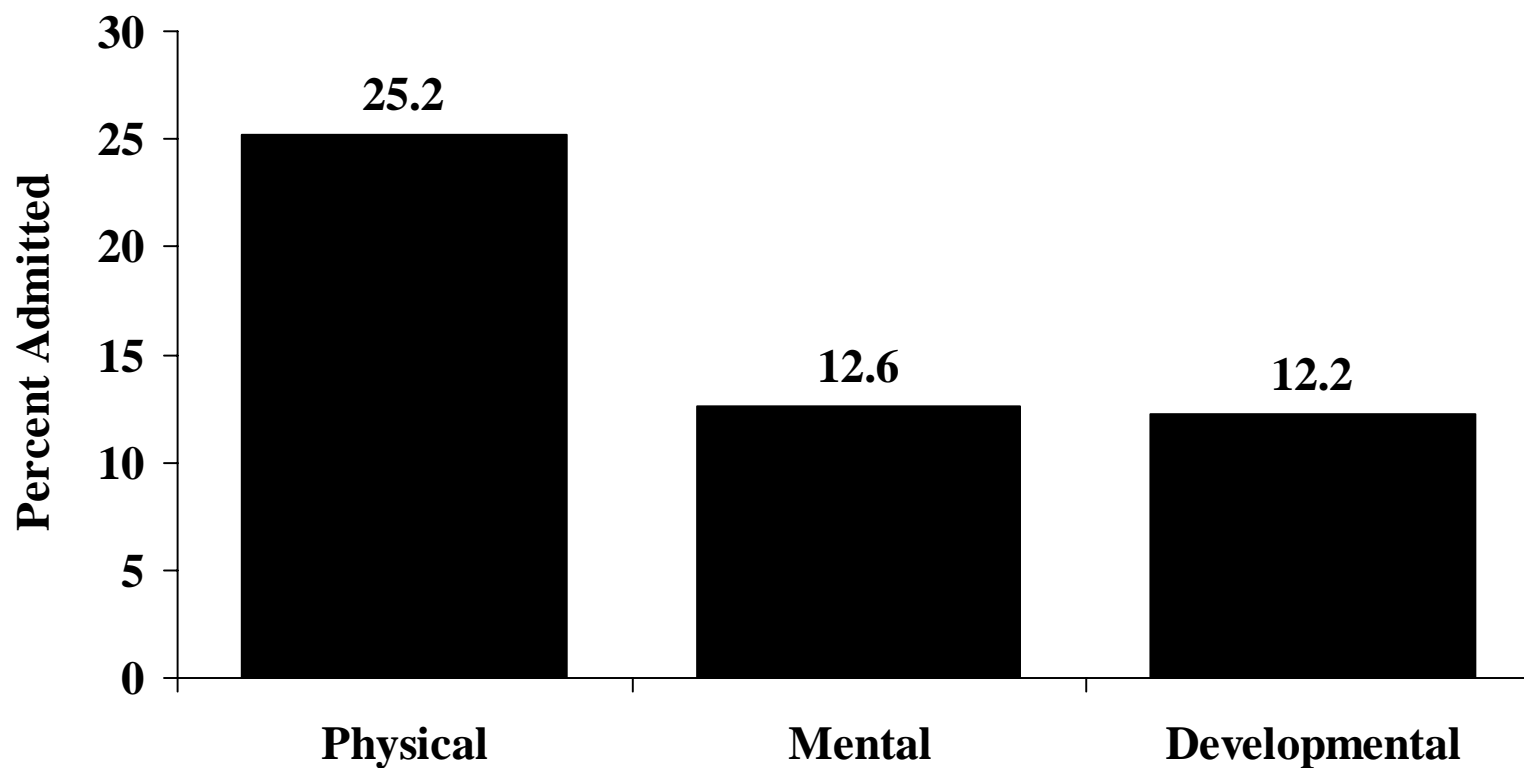
Average Hospital Admissions per 1000 children (0-48)**

Average Hospital Admissions per 1000 children with physical disabilities	416.5
Average Hospital Admissions per 1000 children with mental disabilities	699.6
Average Hospital Admissions per 1000 children with developmental disabilities	405.2
Average Hospital Admissions per 1000 children with developmental disabilities	158.2

Data Source: Caregiver Survey

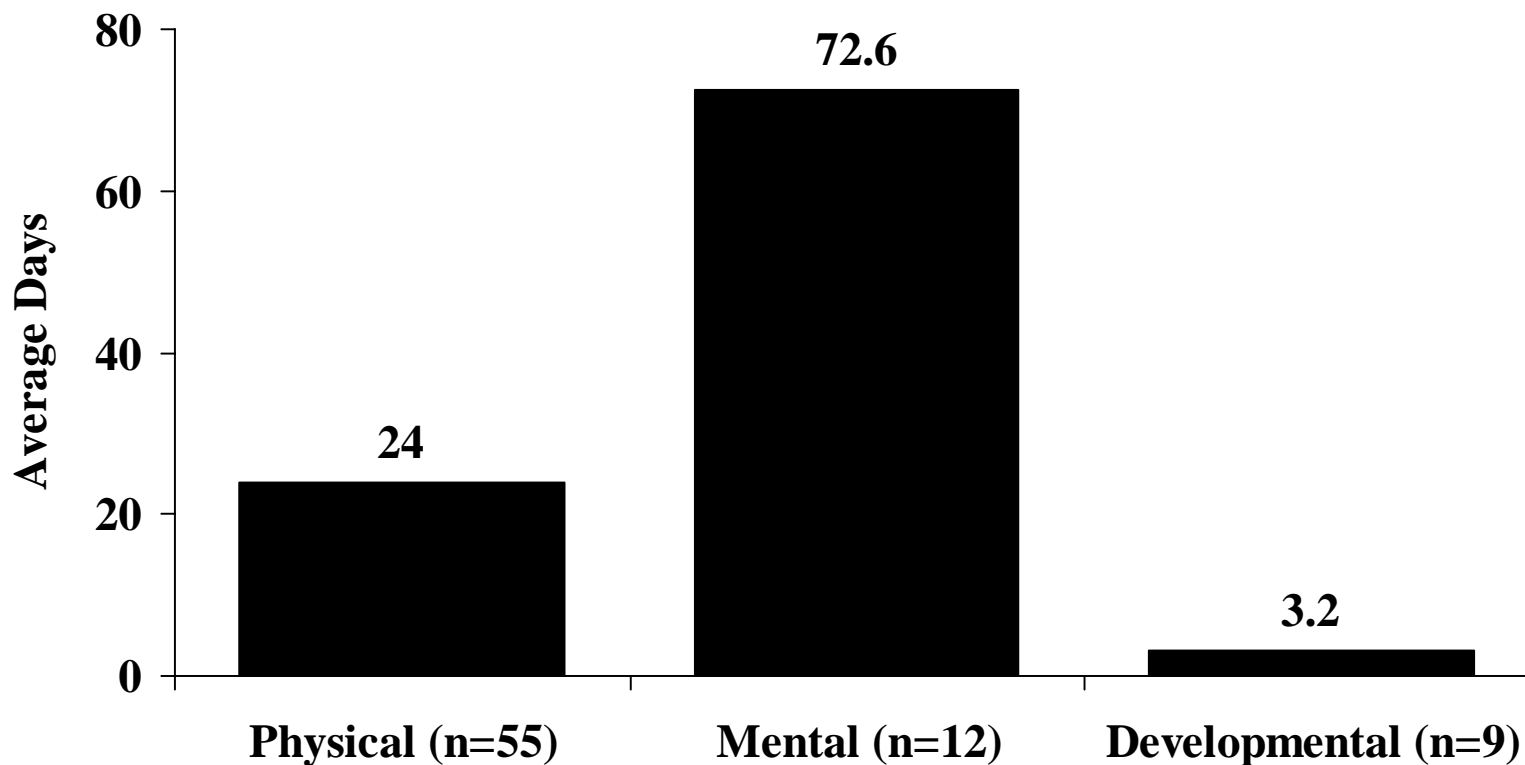
** () = Range of values

**Figure 8: Ever Been Admitted to Hospital
in Past Year By Disability Category**



Data Source: Caregiver Survey (n=257)

Figure 9: Average Number of Days Spent in Hospital for those Hospitalized in Past Year By Disability Category



Data Source: Caregiver Survey (n=257)

Satisfaction with Care

Table 11 shows that overall satisfaction with the provider=s care for the child=s primary disability was high. Ninety-five percent (94.7%) of the caregivers were satisfied or very satisfied with their child=s last visit to the doctor or provider.

Areas that need improvement (i.e. over 10% of caregivers were not satisfied) were doctor=s knowledge of primary condition, length of time it took to get an appointment, and doctor=s response to referral request.

TABLE 11: SATISFACTION WITH CARE
Percent of Caregivers who are...

	<i>...Not Very Satisfied</i>	<i>...Satisfied</i>	<i>...Very Satisfied</i>
Length of time to get appointment	10.9	39.7	49.4
Doctor's personal manner	2.6	40.2	57.3
Doctor's knowledge	12.7	40.2	47.1
Way Doctor talked to caregiver	7.8	42.8	49.5
Involvement in decision making	6.7	41.8	51.5
Doctor's response to referral requests	10.7	36.7	52.6
Overall visit	5.2	45.0	49.7

Barriers to Care

Caregivers of children with disabilities face many barriers to care. The survey measured eight barriers faced by caregivers. Table 12 shows the results of this analysis by disability category. The majority of caregivers "feel overwhelmed a lot due to child needs." Caregivers of children with mental disabilities had the highest rate of feeling overwhelmed. Eighty-three percent (83.4%) of caregivers of children with mental disabilities felt overwhelmed compared to 50% of caregivers of children with physical disabilities.

In six of the eight categories, a higher percent of caregivers of children with mental disabilities faced barriers to care. Caregivers of children with mental disabilities were twice as likely not to get support from family and friends and were more likely not to be able to work or find childcare.

TABLE 12: BARRIERS TO CARE FACED BY CAREGIVERS BY DISABILITY CATEGORY

	<u>Physical</u>	<u>Mental</u>	<u>Developmental</u>
<i>Percent of Caregivers who...</i>			
...feel overwhelmed a lot due to child's needs	50.1	83.4	58.2
...are unable to work due to caretaking responsibility	43.2	54.1	49.0
...find interpreters are not available (n=35)	42.8	54.2	12.7
...are unable to find child care	24.1	36.1	28.6
...do not get support or help from family/friends	22.0	52.1	21.9
...are unable to get transportation to doctors	19.7	27.2	30.1
...do not get enough information from doctor	21.8	18.3	20.6
...are unable to get parking near doctor=s office	13.4	11.1	14.9

Unmet Health Needs

Caregivers were asked about 28 medical and support services that children with disabilities need. Table 13 shows the list of services, the proportion of children who need each service, and the availability of each service for those children who need it. To determine the unmet need for a particular service, the percentages in Table 13 were applied to the 4,314 children with disabilities or fee-for-service Medicaid. Table 14 lists the top ten unmet needs identified by caregivers. The majority of needs identified were support services for parents and caregivers to address the increased caregiving demands of children with disabilities. Needs of parents included support groups, information on their child's disability, respite care, transportation, child care, and parent education classes. Parents also identified some direct service needs of their children including dental care, mental health counseling, case management and over-the-counter drugs.

Table 13 - Availability of Services for RI Children/Adolescents with Disabilities

Medical and Support Services	% of Children Who Need This Service (as reported by caregiver) (n=257)	Of those children who need service....		
		...% service is not Available	...% service is available, does not meet child=s needs	...% service is available, meets child=s needs
Physical therapy	34.6	21.7	16.0	62.3
Occupational therapy	45.0	25.3	13.0	61.7
Speech therapy	54.9	16.3	21.0	62.7
Sensory integration therapy	16.8	35.6	18.6	45.8
Respite care	36.0	83.4	6.4	10.2
Skilled nursing care (4-8 hr shift)	6.2	54.0	2.0	44.0
Certified nursing asst./home health aid	10.6	72.4	12.3	15.2
Homemaker services	8.2	94.1	1.2	4.7
Mental health counseling	41.7	40.8	17.1	42.1
Case management/care coord.	33.5	48.2	15.9	35.9
Nutrition counseling	25.0	54.6	7.1	38.3
Support groups for parents	46.7	66.9	10.4	22.8
Parent education classes	27.8	60.0	17.8	22.2
Information on primary condition	50.8	58.8	10.2	31.0
Prescription medications	55.5	3.1	7.8	89.1
Over the counter drugs	50.3	54.5	23.0	22.0
Eyeglasses	29.9	15.6	33.5	50.8
Durable medical equipment	22.3	10.8	17.0	72.2
Assistive technology	20.4	34.5	39.5	26.0
home modification	8.6	29.9	41.6	28.5
repair of medical equipment	10.1	12.8	3.9	83.3
training on use of equipment	8.6	3.7	1.6	94.7
Disposable medical supplies	26.2	30.4	14.3	55.3
Transportation	44.8	47.5	17.7	34.8
Day care, after school care	33.2	65.7	8.0	26.2
Primary medical care	99.9	0.0	10.6	89.4
Specialty medical care	91.8	6.4	9.4	84.3
Dental care	94.7	10.5	18.3	71.2

Data Source: Caregiver Survey

TABLE 14: TOP TEN UNMET NEEDS OF CHILDREN*
WITH DISABILITIES ON MEDICAID
(n=4,314)**

<u>Medical/Support Service</u>	<u>Estimated Number of Children with Unmet Need***</u>	<u>Percent</u>
Over the Counter Drugs	1,680	38.9%
Support Groups for Parents	1,560	36.2%
Information on Primary Condition	1,510	35.0%
Respite Care	1,390	32.2%
Transportation	1,260	29.2%
Dental Care	1,160	26.9%
Day Care, After-School Care	1,050	24.3%
Mental Health Counseling for Child	1,040	24.1%
Parent Education Classes	930	21.6%
Case Management	920	21.3%

* Needs of children as reported by caregiver

** Total population = 4,314 RI children ages 1-21 with disabilities on fee-for-service Medical assistance

*** Estimated Unmet Need = (Number of children who need service) X
(% service not available + %service available, but does not meet need)

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APPENDIX 1 - MEMBERS OF SURVEY SUBGROUP

**HEALTH CARE NEEDS OF CHILDREN WITH DISABILITIES
MEMBERS OF SURVEY SUBGROUP
July – October 1997**

<u>Name</u>	<u>Organization</u>	<u>Telephone #</u>	<u>Fax #</u>
Denise Achin	Office of Special Needs Dept. Of Education	222-4600, x2306	222-6030
Roger Avery	Center for Population Studies Box 1916 Brown University Providence, RI 12912	863-2302	863-3351
Lee Baker	Department of Children, Youth And Families	457-4510	
Ann Bisson	Early Intervention Program Division of Family Health Dept. of Health	222-1185, x104	222-1442
Tara Breslosky	Disabilities Prevention Program Division of Family Health Dept. of Health	222-1185, x143	222-1442
Cathy Brown	Medimetrix Dept. of Human Services	464-2193	
Jay Buechner	Office of Health Statistics Dept. of Health	222-4931, x112	273-4350
Marie Citrone	Developmental Disabilities Council Governor's Executive Department (DHS)	464-3191	464-3570
Elaine Clem	Parent Outreach Coordinator United Cerebral Palsy of RI 571 Pontiac Avenue Cranston, RI 02910	467-7432	
Lisa Conlon	Parents Support Network 2950 Post Rd. Warwick, RI 02886	736-8844	
Maureen Corkery	Medical Services Dept. of Human Services	464-2170	
John Fulton	Disease Prevention & Control Dept. of Health	222-1394, x115	

Jane Griffin	MCH Evaluation Dept. of Human Services	464-1585	946-2890
David Hamel	Disabilities Prevention Program Division of Family Health Dept. of Health	222-1185, x134	222-3816
Jana Hesser	Office of Health Statistics Dept. of Health	222-4931, x116	273-4350
Dennis Hogan	Center for Population Studies Box 1916 Brown University Providence, RI 02912	863-1656	863-3351
Sharon Kernan	Office of Managed Care Dept. of Human Services	464-3392	943-7218
Gebre Kiros	Sociology Department Brown University – Box 1916 Providence, RI 02912	863-3459	
Tricia Leddy	Office of Managed Care Dept. of Human Services	464-2127	943-7218
Bill McQuade	Office of Managed Care Dept. of Human Services	464-3584	943-7218
Doreen McGonoghy	PALS (Parents and Friends For Alternate Living) DD Council/DHS	942-7050	
Mary Lou Paquette	Early Intervention Program Division of Family Health Dept. of Health/ 32 Sunset Drive West Kingston, RI 02892	539-7147	539-8241
Anne Roach	Medical Services Dept. of Human Services	646-2170	464-3496
Lisa Schaffran	RI Parents Information Network 500 Prospect Street Pawtucket, RI 02860	727-4144	727-4040
Kelly Simmons	SSI State Team Dept. of Health/ 4 Brady St. Warren, RI 02885	245-7399	
Dawn Wardyga	Disabilities Prevention Program Dept. of Health & Parent Advisory Bd. For Hasbro Children's Hospital	222-1185, x149	222-1442

APPENDIX 2 - SURVEY INSTRUMENT



HEALTH CARE NEEDS OF CHILDREN WITH DISABILITIES SURVEY



Conducted by: MCH Evaluation, Inc.
for the Office of Managed Care, Department of Human Services and
Disability and Health Program, Department of Health
October, 1997

HEALTH CARE NEEDS OF CHILDREN WITH DISABILITIES SURVEY

Parent/ Caregiver's Name:	_____	Dates of attempt/follow-up:	_____
Address(es):	_____		_____
	_____		_____
Phone:	_____		_____
Child's Name:	_____		_____
Survey ID:	_____		_____
Other:	_____		_____
	_____		_____
	_____		_____
	_____		_____
	_____		_____

INTRODUCTION TO PHONE CALL INTERVIEW

Hello, this is _____ calling on behalf of the Department of Health and Department of Human Services. We sent you a letter a few days/weeks ago inviting you to answer survey questions about <NAME> born on _____.

We are talking to parents and caregivers so we can improve services to children and teenagers with special health care needs.

Are you the person who is <NAME'S> main caregiver or who knows the most about his/her medical and health care?

Did you receive the letter? (If no, May I read it to you?)

Do you have any questions?

The survey takes about 15 - 20 minutes.

Do you have time now or can I call back at a better time?

All the information you give in this survey is confidential and no one who participates in this survey will be identified in any way. You only have to answer questions you feel comfortable with. There will be no effect on <NAME'S> services or benefits whether or not you participate and if you choose to participate, your answers will not affect <NAME'S> services or benefits. Everyone who is asked to participate will be sent a resource packet of statewide medical, social, and support services.

FILL OUT THIS SHEET FOR ALL 400 RANDOMLY SELECTED CASES

1. Survey ID Number _____
2. MID Number _____
3. Recipient's Date of Birth _____/_____/_____
4. Recipient's Age _____
5. City/Town of Residence _____
6. Lang/Race _____/_____
7. Sex/Grade/Marital _____/_____/_____
8. Date Started SSI (Mo/Yr) _____/_____/_____
9. Active/PMC/SMC _____/_____/_____
10. Other disabled/HH size _____/_____
11. Household annual income _____,_____/_____
12. COA/AidCat _____/_____
13. Body System (SSI) (1-14) _____
14. MMIS Resource Category(original/Update) _____/_____
-

15. Number of Attempts to Contact Caregiver _____

16. Follow-up Status _____

1 = Able to contact caregiver/ACTIVE(at least 6/96-6/97)

2 = Able to contact caregiver/INACTIVE/CLOSED

3 = Able to contact caregiver/declined interview

4 = Unable to contact caregiver/moved out of state

5 = Unable to contact caregiver/whereabouts unknown

6 = Deceased

7 = Other

17. Date of Actual Interview _____/_____/_____

18. Where does <NAME> currently live?
- | | |
|---|---|
| Home with birth/adoptive/step-parent(s)..... | 1 |
| Home with other relative(s)..... | 2 |
| Home with foster parent(s) (not relatives)..... | 3 |
| Group/residential home..... | 4 |
| Hospital/Institution..... | 5 |

19. What relation are you to <NAME>?
- | | |
|---------------------------------|---|
| Parent/guardian _____ | 1 |
| (Fill in) | |
| Case manager/Social worker..... | 2 |
| Health provider..... | 3 |
| Other _____ | 4 |
| (Please specify) | |

20. Please describe <NAME'S> primary disabling condition in the past 12 months. (If more than one, select the one which requires most time spent with the doctor/provider).

(NOTE: I will call _____ <NAME'S> primary condition throughout interview.)

21. Does <NAME> have any other disabilities or medical conditions that require care or medication? (If yes, how many? None = 00)

List Conditions _____

22. How old was <NAME> when primary condition was first diagnosed? (Birth = 00)

_____ If 00 go to 2

23. Is this primary condition a result of an injury?

No.....	0
Yes _____	1
(Please specify injury)	

24. Does <NAME> need the help of other persons with his/her personal care needs, such as eating, bathing, dressing, or getting around the house?
- No..... 0
- Yes(for any)..... 1
25. Is <NAME> able to take part at all in the usual kinds of activity done by most children his/her age? (<5 play,5-17school,18-21work)
- No..... 0
- Yes..... 1
26. Is <NAME> limited in the kind or amount of activity he/she can do because of any impairment or health problem?
- No..... 0
- Yes..... 1
27. In the past 12 months how many days of (play/school/work) did <NAME> miss due to (primary condition)?
- _____
28. Do you consider <NAME'S> disability a....
- A.physical disability (asthma, heart disease)
- No..... 0
- Yes..... 1
- B. ...behavioral or emotional disability
(attention deficit disorder, depression,drug addiction)
- No..... 0
- Yes..... 1
- C. ...developmental disability (mental retardation, sensory impairments)
- No..... 0
- Yes..... 1
29. Have the terms technology dependent or medically fragile ever been used to describe <NAME> ?
- No..... 0
- Yes..... 1

30. In the past 12 months did <NAME> have any other health insurance besides medical assistance (any private, Medicare)?

No..... 0

Yes _____ 1
(Please specify)

31. How many doctors (or providers) did you call before you found one who would accept medical assistance? _____

32. Do you pay any out-of-pocket expenses (not covered by insurance) that relate to <NAME> primary condition for.....?

	No	Yes	If Yes, Average Monthly Amount
A.... medical care (doctor visits, hospital, lab services)	0	1	_____
B. ... medical equipment (assistive technology, wheel chairs)	0	1	_____
C.... medication, drugs (including, OTC)	0	1	_____
D.... medical supplies (disposable diapers, dressings)	0	1	_____
E.... transportation/parking (related to medical visits)	0	1	_____
F.... eyeglasses	0	1	_____
G.... other _____	0	1	_____

33. How do you usually get <NAME> to doctor (or provider) appointments?

Drive in own car..... 1
 Friend/relative drives..... 2
 Take a bus..... 3
 Take a taxi..... 4
 Walk..... 5

34. In the past 12 months how many doctor (or provider) appointments has <NAME> missed, if any, due to lack of transportation? _____

35. In the past 12 months how many days of play/school/work has <NAME> missed, if any, due to lack of transportation? _____

36. Now I'm going to ask you some questions about where <NAME> usually goes for different kinds of medical visits or health care.

a. In the past 12 months has <NAME> been to see a doctor (or other provider) for . . . ?

scheduled well visits for "healthy" check-ups or preventive care	...unscheduled sick visits, for acute problems	...specialty care visits (Note: site related to primary condition only)
No, Never been	0	0	0
Yes	1	1	1

b. If yes, where does <NAME> usually go for . . . visits?
(read all sites)

Private doctor's office	1	1	1
Community health center	2	2	2
Hospital Clinic (specialty care - CDC)	3	3	3
Hospital Clinic - (primary care)	4	4	4
Staff HMO	5	5	5
Hospital emergency room	6	6	6

c. How many different sites does <NAME> go to forvisits?

—	—	—
---	---	---

d. In the past 12 months how many . . . visits did <NAME> have?

(Note: Include total visits, not just at usual site)

— — —	— — —	— — —
-------	-------	-------

e. How many of these total visits were out-of-state?

— — —	— — —	— — —
-------	-------	-------

37. Does <NAME> go to the same doctor for scheduled well visits and specialty care visits?
- No..... 0
- Yes..... 1
38. Is the doctor <NAME> goes to for scheduled well visits a.....?
- ...primary care doctor, like a regular pediatrician or family doctor..... 1
- ...specialist doctor, like a cardiologist or neurologist 2
39. In the past 12 months how many different specialist doctors or providers did <NAME> have appointments with? _____ if 00 go to 41
40. How many of these specialist doctors or providers were out of state? _____
41. How many times has <NAME> been treated in a hospital emergency room in the past 12 months? _____
42. How many times has <NAME> been admitted to the hospital in the past 12 months? _____ if 00 go to 43
- A. How many nights did <NAME> spend in the hospital for this (these) _____ admissions? _____
- B. Were any of these nights in out-of state hospitals? If yes how, many nights? (If no out-of-state put 000) _____

43. On <NAME'S> last visit to the doctor (or other provider) who takes care of <NAME'S> primary condition, how satisfied were you with. . .?

	<u>Not Very Satisfied</u>	<u>Satisfied</u>	<u>Very Satisfied</u>
A. Length of time it took to get the appointment	0	1	2
B. Doctor's personal manner	0	1	2
C. Doctor's knowledge of <NAME'S> primary condition	0	1	2
D. Way doctor talked to you about <NAME'S> primary condition	0	1	2
E. Your involvement in decision making about <NAME'S> care	0	1	2
F. <NAME'S> doctor's response to your request for specialty care referral?	0	1	2
G. Visit overall	0	1	2

44 I am going to read you a list of medical and support services <NAME'S> may have required in the past 12 months. Please tell me if <NAME> needs or requires this service...	0 = no, does not need service 1 = yes, does need service (Go to next column) 2 = don't know	Is service available and does it meet <NAME'S> needs? 0 = Service is not available 1 = Service is available, but does not meet <NAME'S> needs 2 = Service is available and meets <NAME'S> needs
...physical therapy	0 1 2	0 1 2
...occupational therapy	0 1 2	0 1 2
...speech therapy	0 1 2	0 1 2
...sensory integration therapy	0 1 2	0 1 2
...respite care	0 1 2	0 1 2
...skilled nursing care (4-8 hr shift)	0 1 2	0 1 2
...certified nursing asst./home health aid	0 1 2	0 1 2
...homemaker services	0 1 2	0 1 2
...mental health counseling	0 1 2	0 1 2
...case management/care coord.	0 1 2	0 1 2
...nutrition counseling	0 1 2	0 1 2
...support groups for parents	0 1 2	0 1 2
...parent education classes	0 1 2	0 1 2
...information on primary condition	0 1 2	0 1 2
...prescription medications	0 1 2	0 1 2
...OTC drugs	0 1 2	0 1 2
...eyeglasses	0 1 2	0 1 2
...durable medical equipment	0 1 2	0 1 2
...assistive technology	0 1 2	0 1 2
home modification	0 1 2	0 1 2
repair of medical equipment	0 1 2	0 1 2
training on use of equipment	0 1 2	0 1 2
...disposable medical supplies	0 1 2	0 1 2
...transportation	0 1 2	0 1 2
...day care, after school care	0 1 2	0 1 2
...primary medical care	0 1 2	0 1 2
...specialty medical care	0 1 2	0 1 2
dental care	0 1 2	0 1 2
...OTHER _____		

45. Following are some statements that families and caregivers of children with special health care needs have said. Tell me if you agree or disagree with them:

	<u>Agree</u>	<u>Disagree</u>	<u>NA</u>
I am able to find someone to watch my other children when <NAME> needs to see doctor (or provider)	1	0	9
Interpreters are available at doctor (or provider) appointments	1	0	9
I feel overwhelmed a lot of the time due to <NAME'S> needs	1	0	9
Transportation to <NAME'S> doctor (or provider) is available	1	0	9
Parking for doctor (or provider) appointments is close to office	1	0	9
I am not able to work as much as I want due to caretaking responsibilities for <NAME>	1	0	9
I get help and support from friends and family regarding <NAME'S> condition	1	0	9
The doctor (or provider) provides information about <NAME'S> care, diagnoses and available services	1	0	9

46. Are there any other problems you have had trying to get medical care for <NAME> that you would like to tell us about?

47. Are there any other issues we have not asked about that are important to you?

Thank you for taking the time to help us find out how the medical care system is working for children with special health care needs in Rhode Island. Your answers, along with hundreds of others, will help improve our programs. Thanks again.

APPENDIX 3 - LETTER SENT TO CAREGIVER



STATE OF RHODE ISLAND AND PROVIDENCE PLANTATIONS

Department of Human Services
OFFICE OF THE DIRECTOR

Department of Health
OFFICE OF THE DIRECTOR

September 26, 1997

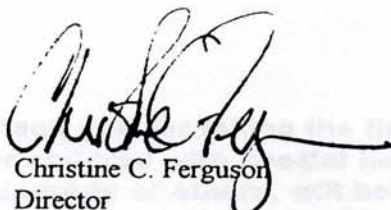
Dear Parent or Caregiver:


The Rhode Island Department of Health and Department of Human Services, along with parents, have designed a survey to find out about the health care of children and teenagers with special health care needs. You have been randomly chosen to participate in this survey. An interviewer will be calling you within the next few weeks to ask you to answer the survey questions. **Your input is very important and will be used to decide how to provide better services to children and teens with special health care needs.** We know you are very busy and thank you for taking time to answer the questions.

The survey takes about fifteen minutes. All the information you give is confidential and no one who participates will be identified in any way. This means that whether or not you participate will have no effect on your services or benefits and if you choose to participate, your answers will not affect your services or benefits. Everyone who is asked to participate will be mailed a packet of information about medical, social, and support services available to families in Rhode Island.

If you have any questions or would like to set up an interview time, please call Jane Griffin at the Survey Office at 277-4900. **Please call us if we do not call you by the end of October because we may not have your correct phone number.**

Sincerely yours,


Christine C. Ferguson
Director
Department of Human Services


Patricia Nolan, MD, MPH
Director
Department of Health


Dawn Wardyga
State Coordinator
Family Voices

APPENDIX 4 - SAMPLE WEIGHTS

	APPENDIX 4: SAMPLE WEIGHTS					
Age	Resource	Sample	Population	Sampling	Basic Weight	
1 to 4	0	13	136	0.095588	10.46154	
	1	16	211	0.075829	13.1875	
	2	22	48	0.458333	2.181818	
	3	10	27	0.37037	2.7	
5 to 11	0	17	479	0.035491	28.17647	
	1	20	981	0.020387	49.05	
	2	24	81	0.296296	3.375	
	3	12	48	0.25	4	
12 to 17	0	18	484	0.03719	26.88889	
	1	17	800	0.02125	47.05882	
	2	19	40	0.475	2.105263	
	3	14	53	0.264151	3.785714	
18 to 21	0	10	405	0.024691	40.5	
	1	16	446	0.035874	27.875	
	2	13	40	0.325	3.076923	
	3	16	35	0.457143	2.1875	
	Total	257	4314	0.059573	16.78599	

APPENDIX 5 - DISTRIBUTION OF PRIMARY ICD9 DIAGNOSES

APPENDIX 5 : Distribution of Primary Disability* by ICD9 Code Groups for Survey Respondents (n=257)		
* Primary Disability as reported by caregiver	ICD9 Code	Percent
PHYSICAL DISABILITY		35.2
Neoplasms	140-239	1.7
Brain Tumor	191	1.1
Neuroblastoma	194	0.3
Lymphoma	202	0.1
Leukemia	204,208	0.2
Endocrine	240-279	2.1
Sotos Syndrome	253	1.1
Metabolic	270	0.3
Wilson's Disease	275	0.1
Cystic Fibrosis	277	0.6
Blood Diseases	280-289	0.5
Sickle Cell	282	0.3
Hemophilia	286	0.2
Nervous System	320-389	17.4
Hydrocephalus	331	0.1
Hemiparesis	342	0.3
Cerebral Palsy	343	8.7
Paralysis	344	1.4
Epilepsy	345	1.4
Muscular Dystrophy	359	0.9
Blind	369	2.0
Deaf	389	2.6
Respiratory	460-519	2.5
Asthma	493	2.4
Tracheomalacia	519	0.1
Digestive	520-579	0.1
Short Gut	579	0.1
Genitourinary	580-629	0.2
Kidney	593	0.2
Musculoskeletal	710-739	0.2

Lupus	710	0.1
Muscular disorder	728	0.1
Congenital Anomalies	740-759	4.6
Spina Bifada	741	1.4
Microcephalus	742	0.4
Heart defect	745	1.5
Imperforated anus (digestive)	751	0.1
Scoliosis (musculoskeletal)	754,755	0.3
Gastroschisis (abdominal)	756	0.3
Epidermolysis bullosa (skin)	757	0.3
Prader-Willi (chromosome)	759	0.3
Perinatal	760-779	1.0
Prematurity	765	1.0
III - Defined	780-799	3.1
Seizure Disorder	780	3.1
Injury	800-999	1.8
Traumatic Brain Injury	854	0.8
Fracture	813	0.9
Near Drowning	994	0.1
MENTAL	290-319	27.3
Schizophrenia	295	0.1
Manic depression/psychoses	296	1.7
Anxiety	300	0.8
Emotional/behavioral (dx unknown)	307	7.6
Post Traumatic stress	309	0.1
Attention deficit disorder (with and without hyperactivity)	314	17.0
DEVELOPMENTAL		37.5
Autism	299	2.5
Learning disability, pervasive developmental delay	315	18.1
Mental retardation	317	11.1
Down Syndrome	758	2.6
Speech disorder	784	3.2

*Primary disability as reported by caregiver